

Reflective Piece

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MY JOURNEY AND THE VALUE OF A COMMUNITY
WHERE NEURODIVERSITY IS CELEBRATED

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INTRODUCTION

The purpose of this article is to share some background about how I got into this educational space, my experience of being diagnosed with dyslexia and then disclosing myself to my peers at the inaugural Neurodiversity Symposium held at Otago Polytechnic in November 2021 as an adult academic. This provides a unique perspective on my experience as a neurodivergent individual in a neurodiverse world. I had no idea how much a community of practice, one in which I can learn, would help me grow, and how belonging to a community would make me feel valued, until I spoke at the symposium. This growth is something I am celebrating today.

BACKGROUND

School years

While at school, I involved myself in everything I could. However, while I enjoyed learning new skills and activities, I found myself running away from primary school as I could not understand what the teachers were saying. I always seemed to not quite get what the teachers were talking about. This made me frustrated, it left me feeling overwhelmed and lost. At that time, I never fully understood why I felt LOST! – and sadly nor did my parents.

At intermediate school and then high school, I noticed that I was learning at a different rate to my friends. Once again, I could feel myself getting lost in the crowd. My reading and attention were drifting in and out; trying to find a book to read for English was near impossible. I couldn't stay focused, yet I was expected to sit still and concentrate, something I was not very good at doing. I realised I could not hide any longer.

After gaining School Certificate, I left school in the first term of the sixth form. I was a high-school dropout, not that I thought that at the time. At that time in my life, I thought I had a plan; in reality, I now realise that I had no idea what I wanted to do with my life or where I wanted to be. All I knew was that I was ready to leave educational learning; with that, I entered into the world of retail.

Being neurodiverse did little to improve my confidence in my academic studies. Growing up not knowing why I did not learn the same way as others did little to help my belief in myself. It was not until my children were at high school that I decided I wanted to spend time working on my career. I decided to train to be a personal trainer and then a massage therapist, and thus I started on my first study in higher education.

I did not enjoy reading at school, so my biggest obstacle once again was getting back to the books. I was not sure how I was going to do this: undertaking academic work. I was determined to start and finish this learning journey; to complete the qualification especially, as I had left school early. With the help of my husband, who would proofread all my work before I handed it in, I achieved my qualification; I had done it.

Irlen Syndrome and dyslexia

I was diagnosed with Irlen Syndrome (IS) in a routine vision check-up. Irlen Syndrome is commonly defined as a perceptual processing disorder, suggesting that the brain cannot correctly process visual information due to sensitivity to specific wavelengths of light. Symptoms include poor concentration, difficulties with reading, writing and comprehension; glare sensitivity; headaches and poor depth perception. These are all symptoms I have experienced, and some are heightened if I get tired, overwhelmed or am under pressure.

I did not realise that I had a learning disability before receiving the diagnosis. I believed that all people saw words in the same manner, so I had not thought of investigating why I saw things this way or what effect this may have had on me throughout my education; I just accepted it. While investigating IS, I discovered that dyslexia often co-exists with IS (Australasian Association of Irlen Consultants, 2021). The more I investigated this, the more I thought I could also be dyslexic, which could explain why I have struggled with learning. I now have a pair of glasses with pink lenses that flatten the words out, stop them moving and let me concentrate for extended periods of time.

Diagnosis

Getting a diagnosis by going through an adult cognitive and educational assessment (ACEA) and recognising that I have many “workarounds” that allow me to cope led me to reflect on my capabilities rather than my deficits. For me to even get this ACEA was an obstacle in itself. I had to get in touch with SPELD New Zealand, then they had a certified tester email me; this took a few months to set up. For me this was worth the wait.

NEURODIVERSITY SYMPOSIUM

The exciting journey to the Neurodiversity Symposium coincided with my Master’s studies, in which I had decided to explore how lecturers can create learning experiences that not only include and take account of the challenges faced by neurodiverse learners, but also utilise and enhance the capabilities that neurodiverse learners bring to the classroom. I then saw a posting on Tūhono advertising the launch of the Neurodiversity Symposium. Several of my colleagues suggested I express my interest in presenting, as it could provide an opportunity for me to share my experiences, my learning journey and the rationale for why I wished to pursue this topic in a Master of Professional Practice.

As part of the symposium, I publicly revealed my diagnosis of dyslexia and Irlen Syndrome, accompanied by colleagues and other like-minded individuals with an empathic ear, for the first time. Strangely, I found myself standing in front of a crowd doing this! I am a neurodivergent individual, and I will embrace it all.

Neurodiversity, according to Clouder et al. (2020, p. 757), is “an umbrella term” that encompasses many learning disabilities, such as “dyspraxia, dyslexia, activity deficit hyperactivity disorder, dyscalculia, autism spectrum disorder, and Tourette syndrome.” They add that the rising number of learners with learning disabilities linked with neurodiversity enrolling in higher education presents a widespread and developing challenge for lecturers and businesses worldwide.

Deciding to present at this symposium was a big deal for me as I felt extremely vulnerable in opening up and telling people something so raw, sensitive and emotionally charged for me. I needed some time to reflect on this opportunity. After consulting with my husband and academic mentors, I decided to take this opportunity. I decided that it provided the ideal option for me to be exposed to a safe and comfortable environment surrounded by empathy and understanding. It also provided an opportunity for new learning. I knew there was no turning back once I decided to present. I had no idea at this stage that the Neurodiversity Symposium was

going to be a place where I would feel like I had been 'hugged' and 'valued' for speaking my truth, as I had always worked long and hard at hiding my 'weaknesses.'

Putting my presentation, including slides, abstract and bio, together and talking about myself was quite an exciting process. How much do I want to divulge? How much should I say? What did I want to talk about – just me or ... more?

When designing my presentation, I used quotes from the literature on neurodiversity that I had discovered while studying for my Master's degree. I also added my own perspective and described the strategies I apply, referring to them as my "workarounds." I have developed these over the past 53 years to make myself appear to understand, to not stand out in a crowd in a negative way, or maybe conceal my lack of understanding.

As I put all of this together, I found myself wondering what my motivation was, and why I felt the need to tell my story now. Exactly why did I want to do this? Why was I willing to let go, to face colleagues, students and peers, and for them to see me in a different light? I was in it for the greater good. I want to share my story so that others can learn, and I can hear theirs. I want to educate, empower, encourage and care for others, and understand what I can do to help people achieve their full potential. I have a gift of encouraging people to open up to me. Therefore, this was something I had to do. This was my opportunity.

WHAT I KNOW FROM THE LITERATURE ABOUT NEURODIVERSITY AND DYSLEXIA

Some of the literature I have encountered in my research has been very insightful, and I have enjoyed reading that neurodiversity is and can be normalised. I have investigated what other adults have discovered about themselves and how they have accepted their neurodiversity later in life. I was interested to learn if they had found or created their own "workarounds."

In my research, I also found that neurodiversity is a relatively new term. Singer (1999) coined the term neurodiversity to refer to the fact that all humans have a unique brain, made up of our genetic heritage (Nature) and cultural and experiential memories (Nurture). Researchers Cameron and Billington (2017) discussed dyslexia in the United Kingdom, describing it as a set of cognitive or neurological deficits that affect one's reading ability.

Snowling et al. (2020) found that for many years researchers evaluated dyslexia as a specific learning disability – evident in the sense that it is difficult to explain using obvious causes (sensory problems or low IQ). However, the inability to identify significant differences in reading and phonological skills between dyslexic children and children with more general learning problems has caused this opinion to lose favour (Snowling et al., 2020).

According to SPELD New Zealand (n.d.), a specific learning disability is a combination of unexpected learning difficulties that significantly interfere with an individual's academic, work or everyday life activities. On the other hand, Mirfin-Veitch et al. (2020) believe any definition of neurodiversity should make it clear that it is not a diagnosis but rather a title that encompasses a wide range of specific, non-specific, hidden and/or undetermined diagnoses, such as intellectual disabilities (ID), communication disorders (CD), autism or autism spectrum disorder (ASD), attention-deficit/hyperactivity disorder (ADHD) and specific learning disorders (SLD).

Through my continuing research, I discovered Hayes's (2020, p. 41) findings that, from the 1960s to the 1980s, dyslexia was often dismissed. Dyslexia was once frequently referred to as a "middle-class disease." Parents felt that the blame fell on them for not helping their children with their studies. Hayes goes on to say that in the late 1960s, dyslexia was thought of as "educational nonsense," whereby middle-class parents made excuses for the lack of academic ability of their children. I'm not sure if my parents agreed with this. All I know is that my mother tried her best, and steered me towards sport, which I was good at.

Hayes (2020) outlines that in the 1980s dyslexia and other learning difficulties were finally recognised by the government as specific learning difficulties (SLD), resulting in funding being made available, along with statements of educational need regarding those who had been appropriately assessed and identified. From my own experiences, discovery and acceptance of dyslexia in Aotearoa New Zealand's education system was not a reality. I do remember some of my friends receiving additional support for reading. I must have flown below the radar, as this was never offered to me. These earlier interventions would have assisted throughout my schooling and may have resulted in my academic ability pathway being more straightforward.

From children's education to tertiary education

MacCullagh (2014) found that dyslexics and other learners with learning differences face significant challenges as a result of poor understanding and acceptance of their disability as a social construct. Recent literature discussed in this essay highlights the importance and value of supportive lecturers, mentors and coaches to improve outcomes for learners with neurodiversity. In their review, Waters & Torgerson (2021) documented pockets of the historical development of some interventional strategies used to support learners with dyslexia in higher education. The effectiveness of some or all the processes, particularly when it comes to in-class adaptations and mentoring, can only be established through further experimental research. This systematic review points to numerous surveys that raised concerns about student satisfaction, so there is a likelihood that problems persist in practice.

Aotearoa New Zealand researchers Dymock & Nicholson (2013) found that support from lecturers can make a significant difference to the life and learning of a dyslexic adult. Waters and Torgerson (2021) supported this finding by highlighting the importance of introducing mentors or coaches to improve learner outcomes. Adult learners with dyslexia must have someone who is there for them, who understands what it is like for them and who is willing to adapt their teaching to help them. MacCullagh (2014) highlighted the inadequate research into the participation and experience of learners with dyslexia in higher education. This participation is very important and, while lecturing, I have found myself including my personal experience by adapting my teaching style to help learners improve their outcomes, by giving the class some real-life examples.

After just completing an online course in phonological skills, I benefited from further guidance and understanding on the subject of breaking down sounds and syllables, skills I needed earlier in my childhood. How did I fall through the cracks, and why was this weakness not found early on? Maybe I should not go there in terms of 'why not,' but rather see it as: "I want to ensure young people do not fall down the cracks and that the right tests and measures are put in place at a much earlier age." These basic skills are so crucial in all areas of learning.

Recent research in educational settings within New Zealand has highlighted significant challenges for neurodiverse learners. Mirfin-Veitch et al. (2020) discovered that in Aotearoa New Zealand, a lack of understanding of neurodiversity in the schooling sector negatively impacts the lifelong educational experiences of learners labelled as neurodiverse.

Increased awareness

On the one hand, there is increased awareness that neurodiversity can be a barrier to young people being part of the drive "to build the world's best education system for all New Zealanders, and provide a range of different types of learning environments and settings to meet the needs of children, young people and their parents and whānau" (Hipkins & Martin, 2019, p. 4) – cited in the New Zealand Ministry of Education (MOE) learning support plan 2019-2025 that Aotearoa New Zealand is committed to building. There remains, nevertheless, a great deal of learning and understanding required about how to identify neurodiversity and, subsequently, how to meet the learning aspirations of neurodiverse learners.

Mirfin-Veitch et al. (2020) identified five key themes that emerged from a systematic process of identifying educational research that could provide easily implemented, low-cost, flexible supports for neurodiverse learners:

1. Prioritising and valuing relationships
2. Developing agency
3. Supporting learners' behaviour understanding and management
4. Creating inclusive environments
5. Embedding inclusive teaching strategies.

New approaches to and understandings of neurodiversity/dyslexia are explained by Stenning and Rosqvist (2021), who describe neurodiversity as a collective property of brains, as we attempt to negotiate between us what it is to be human and how we can work together to lead successful lives and lessen suffering. They propose investigating the implications of neurodiversity for autism research and that we unravel the analogy between neurodiversity and biodiversity (Stenning & Rosqvist, 2021).

Waters & Torgerson (2021) have advanced an argument for establishing and evaluating dyslexia-trained mentors. Several studies have discussed using a "learning catalyst" (mentor or coach) to facilitate learning during task execution. A third person in a role like this appears to help learners with specific learning difficulties. However, there are no published studies of a causal design that evaluate the use of mentors as a "learning intervention" using measurable outcomes. In my Master of Professional Practice (MPP), my academic mentors have taken on this role and are guiding me through the journey of completing my Master's. The results of their support have given me the confidence to believe in myself, to step out of my comfort zone, and trust that I too can keep learning no matter what hurdles are out there.

Understanding the history and context of the Aotearoa New Zealand educational system and of attitudes to neurodiversity has assisted me to understand why I was able to fly under the radar while having learning challenges. I believe I was able to be successful in my academic endeavours due to valued relationships with supportive and inclusive teachers/mentors and coaches throughout my life. I have managed to find support among those who have had to teach me – no one, not even myself, had any idea that I suffered from significant learning challenges. I am 'normal.'

THE BIG DAY – THE NEURODIVERSITY SYMPOSIUM

Attending and Presenting

I started my day by going for a run. In my mind, as I was getting ready to leave home, I thought about my presentation and what I was going to say. Being neurodivergent was an enormous challenge for me, and I felt highly vulnerable.

Once I arrived at work a colleague offered to look over my presentation because of my reactions to reading it over the last week or so. I'd been very tearful and sometimes sobbing. I needed to get that under control. I found out that the second time I read it on the practice days was always better than the first, so at 7:44 a.m. on Thursday I presented to one person. It went without a hitch – and what I mean by that is I did not cry. Having a peer work with me through this was very valuable. In studies of peer collaboration, students have found that they can learn to value and perceive one another more positively when they know the value of cooperation among peers (Ncube, 2011).

I felt empowered and strong and knew that I had other colleagues and friends supporting me on this day. I knew from my research that the literature showed that with increased knowledge, neurotypical students are more

likely to understand their neurodiverse peers and support them for being who they are (Rentenbach et al., 2017). This made me feel very proud that the community of peers I have gathered around me respect me as a lecturer and are with me on my journey of discovery.

Other duties

One of my other duties on the day was to meet and greet our keynote speakers, Jolene Stockman and her husband Mike Styles, outside so we could all walk in together. The keynote speakers were both incredibly talented and courageous individuals. Jolene has presented fantastic team talks in her career, expanding on and talking about her autism. Mike is renowned for his research on dyslexia and is currently working on a book which is close to publication. The title is *Congratulations – You Have Dyslexia: Great Minds Think Differently*. Exploring the link between dyslexia and Irlen's is proving to be a success story.

I was the third speaker on the run sheet for the day. We had a group talk about learning and different teaching aids from the learning and teaching team. Then we heard another neurodiverse practitioner, and the lecturer gave a speech. Then it was me. The anxiety was horrific, frankly, but I got up there and started talking. Coming to that dreaded third line, "This is the first time I have spoken publicly about my diagnosis and my Master's," I felt myself tear up and pull myself together, but as I spoke, I felt empowered. I had done my homework. I had done my research. I was ready!

Communities of practice

Otago Polytechnic is establishing a participatory community of learners and educators interested in understanding neurodiverse experiences and how to maximise educational success for all. According to Lave and Wenger (1991), a community of practice (CoP) is a group of people with a common interest or concern who meet their individual and group goals. Communities of practice exist both formally and informally in some organisations. There is a great deal of interest within organisations in encouraging, supporting and sponsoring communities of practice to gain new knowledge that could in turn lead to higher productivity.

Communities of practice consist of individuals who share a concern or a passion for what they do and learn how to do it better through regular interaction (Lave & Wenger, 1991). We know that best practice for neurodiverse people is best practice for everyone (Lave & Wenger, 1991). Therefore, the goal is to improve awareness and best practice by, with and for neurodiverse learners/taura, educators and staff in both formal and informal ways.

THE FUTURE

What a fantastic day. The community of practice with and for Neurodiversity is going to be incredible. We all know that people blossom when we collaborate and bring our ideas together, and this is precisely what this community of practice is going to do. It has not only empowered me, but my worldview is also changing. I don't feel as vulnerable as I did. I am not as tearful as I was. This experience has made me feel empowered. I was driven to make a difference. I noted that all neurodiverse people are very different. We can all be diagnosed with similar learning disabilities; we all have some common threads; we can find reading, spelling and grammar challenging, and some like reading slowly or trying not to read at all. In contrast, I speed-read now or skim to get the idea of what I'm reading, but everyone is unique, and diverse. We are colourful in our diagnoses.

I was determined to make this work for me. I have struggled with feeling out of place, and now my eyes are wide open. The feeling of being misunderstood for a long time is slowly slipping away. I can be myself, embrace what I am learning, and take on the challenge headfirst. And I will proudly be called Neurodivergent.

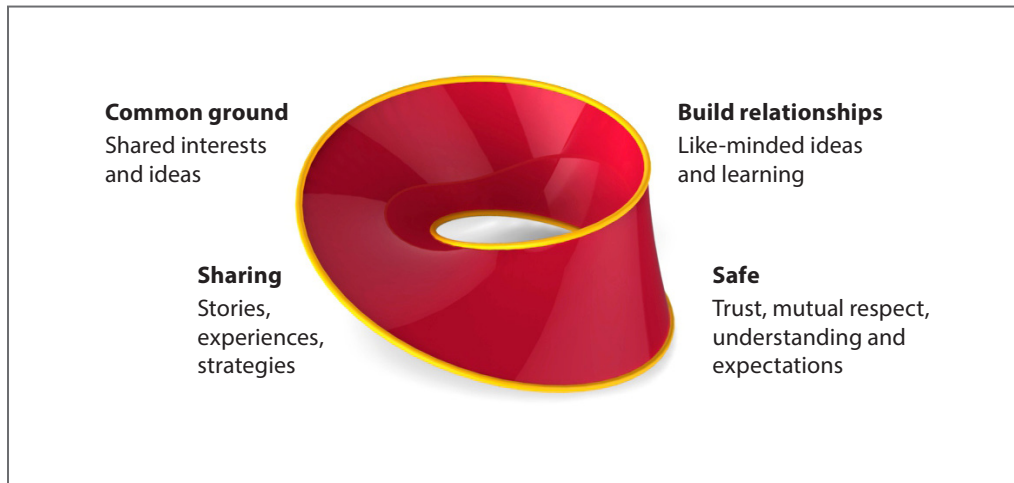


Figure 1. Building my community (Rachel van Gorp, 2022).

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CONCLUSION

I believe the Neurodiversity Symposium was a success as it highlighted the diversity of staff and learners with neurodiversity. Some exciting ideas surfaced, such as that learners with neurodiversity learn better if they have someone available for them, who understands how they feel and is willing to adapt their teaching style to support them to succeed. With the community of practice emerging and the associated networking, this event highlights the strengths that neurodiverse students and staff bring to the community. Otago Polytechnic will grow more vital in supporting our learners to be successful through recognising the capabilities that neurodiverse learners can obtain in the classroom and how we, as lecturers, can use these abilities to improve our teaching.

Rachel van Gorp is a senior lecturer in the School of Business and a facilitator at Capable NZ, Otago Polytechnic. Rachel brings to her teaching a background in banking, personal training, massage therapy, business ownership, mentorship and many volunteering roles. Rachel has interests in teaching and learning with neurodiverse students. She is currently undertaking her Master of Professional Practice with a focus on “neurodiversity in the classroom: awareness and practice.”

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